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Caregiver, Physician, and Nurse Preferences of Nutritional Support in Bone Marrow Transplant Unit

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CAREGIVER, PHYSICIAN, AND NURSE PREFERENCES OF NUTRITIONAL SUPPORT IN BONE MARROW TRANSPLANT UNIT

by

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ABSTRACT

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Objective: This study looked at caregivers', physicians', and nurses' preferences of types of nutrition support. Many cancer patients are given enteral or parenteral nutrition support because they cannot obtain nutrients orally.

Design: This is a qualitative study which examined caregivers', physicians', and nurses' preferred type of nutrition support, feelings toward each type, goals regarding nutrition, and how the medical team could help meet those goals.

Subjects: A total of 71 caregivers, physicians, and nurses from the hematopoietic stem cell transplant unit at St. Jude Children's Research Hospital were surveyed, of which were 17 males and 54 females. The ages ranged from 22 to 59 years old.

Results: The results showed the majority of caregivers preferred parenteral nutrition over enteral nutrition, while most healthcare professionals preferred enteral nutrition over parenteral nutrition.

Conclusion: Most caregivers do not know enough about the different types of nutritional support to choose a preference.

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CHAPTER I

INTRODUCTION

Many cancer patients are given nutritional support because they cannot eat or do not have the desire to eat. These patients are placed on either enteral or parenteral nutrition support. The purpose of this research was to study if hematopoietic stem cell transplant parents/caregivers, physicians, and nurses preferred parenteral nutrition or enteral nutrition and what their perceptions were toward both types of nutrition support. A survey was completed by hematopoietic stem cell transplant physicians and nurses, as well as parents/caregivers of hematopoietic stem cell transplant patients at St. Jude Children's Research Hospital. The survey included questions about what they thought were the benefits and disadvantages of both types of nutrition support, which type of nutrition support they preferred, and what their goals were regarding nutrition.

The hypothesis was that hematopoietic stem cell transplant physicians, nurses, and parents/caregivers would prefer parenteral nutrition because patients already had a central line in place to receive chemotherapy, so it would be easiest to use that central line to give nutrients that are lacking from oral intake of food.

At St. Jude Children's Research Hospital, most of the patients on the hematopoietic stem cell transplant unit were placed on parenteral nutrition because they were not getting enough nutrients from eating food orally. These patients could not or did not want to eat for reasons such as nausea, vomiting, mucositis, or lack of appetite. The patients were still allowed to eat or drink whatever they wanted while on the parenteral nutrition. For the patients who were still eating some, the parenteral nutrition was more of a supplement to provide nutrients, calories, and protein that were lacking. Before

nutrition support was started on a patient, each patient's oral intake was assessed daily to determine if the patient needed nutrition support. Once nutrition support was started, each patient's oral intake continued to be monitored on a daily basis to determine if the nutrition support was still necessary and if the amount of nutrients, calories, and protein should be increased or decreased based on the patient's oral intake of food. If a patient on nutrition support started eating well again, then nutrition support would be discontinued.

St. Jude Children's Research Hospital was based around patient family-centered care. Patient family-centered care is an approach to healthcare that focuses on the family as a child's primary source of strength, support, and well being. The word "family" refers to two or more people who are related biologically, legally, or even emotionally to the patient. Patient family-centered care is based on the belief that healthcare staff and the patients' families are partners working together to best meet the needs of the child. This study was done because the medical team at St. Jude Children's Research Hospital knew that enteral nutrition was better for the body than parenteral nutrition, but parenteral nutrition was used more because enteral nutrition was not accepted by many caregivers. Therefore, the study was an attempt to find out what caregivers as well as healthcare professionals included in the medical team thought of each type of nutrition support and what their goals were regarding nutrition so that their needs could be better met at St, Jude through patient family-centered care.

Literature Review

What is the difference between enteral nutrition and parenteral nutrition? Enteral nutrition is a way of providing nutrients through a tube placed in the nose, stomach, or

small intestine. Parenteral nutrition is a way of providing nutrients to a person intravenously through a central line bypassing the digestive system. The main goals of nutrition support are to prevent nutrient deficiencies, minimize the effects of starvation, and maintain immune and gut function (1). There are many different opinions on which type of nutrition support is better and whether or not these types of nutritional support give patients a better quality of life. Both of these types of nutrition support are used a lot in pediatric oncology patients.

Parenteral nutrition has seemed to become a primary nutrition route for children with cancer, especially after hematopoietic stem cell transplantation (2,3). This can be because of possible complications associated with enteral nutrition, such as bleeding from the nose or throat (4), vomiting (5), and diarrhea (6). Even if a patient has a good nutritional status before hematopoietic stem cell transplantation, he or she may still need some kind of nutritional supplementation during or after transplantation (7). Some bone marrow transplant patients on enteral nutrition experienced severe diarrhea and bleeding so parenteral nutrition was selected (4). Some healthcare professionals believe that enteral nutrition in the form of a nasogastric tube can be too aggressive because of the risk of vomiting, bleeding, perforation, aspiration, and pain associated with mucositis (5). Enteral nutrition is normally not given to patients with the presence of oral mucositis when determining an option for nutrition support (2). When mucositis develops, there is a higher risk of infection and bleeding with enteral nutrition (3). Parenteral nutrition is also easily accessible through the patients' central line (4). However, parenteral nutrition has shown a higher and earlier incidence of line infections (5), more frequent episodes of fever (8), and risk of liver dysfunction (1). Parenteral nutrition has also been more likely

to lead to other complications such as hyperglycemia, volume overload, and thrombosis (3). However, parenteral nutrition is a good alternative to enteral feedings when a patient does not have a functioning gastrointestinal tract (7). Enteral nutrition has shown many benefits on the gut and has been shown to help patients heal more quickly (3) and has been preferred in patients with a functioning gastrointestinal tract (9). It should be started as soon as possible when needed (1) and has been shown to preserve gut function for later on when the patient may be able to eat by mouth again (10). Some advantages of enteral nutrition include improvement of weight or weight gain of the patient, relief of family stress about eating, and better quality of life for the patient (4,2). Enteral nutrition tubes are also an easier way to give oral medications when the patient cannot take the medications by mouth (3). Enteral nutrition is cheaper and easier to provide than parenteral nutrition, which can help shorten the length of hospital stays as well as decrease complications (8). It has been the most effective with maintaining nutritional status when patients use enteral nutrition for a longer time (10). Nasogastric tubes are a type of enteral nutrition used over a shorter period of time (6). These seem to provide some relief for parents of younger children because it allowed an alternative route for medications (9). Nasogastric tubes have been shown to lead to a reduction in the frequency of central venous catheter handling and infections (5) and are not associated with excess gastrointestinal disturbances or nutrient malabsorption. However some patients have vomited with nasogastric tubes and these patients are normally switched to parenteral nutrition (2). Both enteral nutrition and parenteral nutrition have proven to help bone marrow transplant patients maintain their nutritional status and weight (10). When comparing enteral nutrition and parenteral nutrition, there has been a lower

incidence of diarrhea and fewer complications in the patients on enteral nutrition (2,3). Both of these types of nutritional support have been shown to be beneficial, but there are always a few drawbacks. Each patient has different needs and may require a different type of nutrition support based on those needs.

The parents of pediatric bone marrow transplant patients usually have an initial negative reaction to enteral nutrition, especially if the child fights it or has a negative reaction to the enteral nutrition, but one study showed that three out of four parents changed their feelings toward enteral nutrition once the child was on it and they realized how easy it was to administer. These parents initially perceived enteral nutrition as a threat to the child's self image which put an additional emotional burden on them. These parents even reported that the child's nutritional status improved with enteral nutrition (4). Many parents commented favorably on their improved ability to participate in the care of their child by allowing them to assist in providing nutritional support and to ease the burden of medication administration (9). However, enteral nutrition's tolerance and effectiveness in reversing nutritional depletion after bone marrow transplantation has not been defined very well and is still disputed. It was shown that when enteral nutrition is tolerated, it is effective in maintaining nutritional status after bone marrow transplant. Enteral nutrition was not found to affect bone marrow recovery, length of hospital stay, or general well-being of the patients (2). Some factors in parental acceptance of enteral nutrition are the severity of the child's condition, the degree of the child's poor nutritional status, the child's strong reaction to enteral nutrition, and the child's age because enteral nutrition normally works better in younger patients (4). However,

Weisdorf et al showed an increase in survival of patients who received total parenteral nutrition as well (7).

Oncologists were shown to prefer enteral nutrition over parenteral nutrition because enteral nutrition can help gastrointestinal function and has a beneficial effect on gut mucosal barrier function (4,2). Enteral nutrition is also more natural, less costly, and easier to provide (4,5,2). Langdana et al demonstrated that aggressive enteral nutrition can maintain nutritional status in pediatric bone marrow transplant patients (3). Physicians reported that patients who declined enteral nutrition maintained poor nutritional status which led to delayed cancer treatment. Many doctors recommended enteral nutrition when the child's nutritional status was not improving after a certain amount of time. Most doctors' main considerations when suggesting enteral nutrition are risk of aspiration, child's length of treatment or remaining hospital stay time, and the parents' and child's reaction and preference (4). However, enteral nutrition is perceived as a life-saving therapy (11).

Both types of nutrition support may be perceived differently when the patient is sent home from the hospital. Home nutritional support provides an alternative to staying in the hospital (12). It helps keep patients nourished without having the stress of trying to eat (6). The decision to have home enteral tube feedings should be made as soon as possible to avoid any negative changes in nutrition status (13). Parents and patients usually agree with continuing nutrition support at home after discharge. It has been shown to accelerate recovery and improve general wellbeing (3). In one study, home enteral tube feedings were shown to prevent weight loss and help some patients gain weight (13). However, Bozzetti et al found that the most common outcome from home

nutritional support is maintaining nutritional status, not making it return to normal or better (14). Home enteral tube feedings have been shown to prevent malnutrition (13). Some patients reported having a physically restricted life that controlled their daily routine. These limitations were described as being connected to a pump for long hours and having inflexible infusion regimens that did not fit the patient's lifestyle. Home nutrition support can also make traveling outside the home challenging. Patients on home parenteral nutrition stated that they feel like they are hooked up and tied down, but happy to be alive. These patients agreed that the lifesaving benefits of the parenteral nutrition far outweighed the annoyance of the parenteral nutrition equipment and supplies (11). Younger patients normally have better outcomes on home nutritional support than older patients (14). Most patients prefer receiving home parenteral nutrition at night so they can live a more normal life during the day. Patients and family members were found to have a sense of relief by feeling less pressure to eat with home parenteral nutrition. Some positive features of home parenteral nutrition were related to a sense of relief and security that nutritional needs were met, as well as an increase in energy. Patients on home parenteral nutrition were not found to skip meals. They were able to enjoy meals without the pressure of having to eat enough. There were a few negative side-effects of home parenteral nutrition described by patients including nausea, vomiting, drowsiness, and headache that were perceived as being due to the home parenteral nutrition infusing too quickly or in excessive quantities. The home parenteral nutrition also affected some patients' sleep. Some patients felt that the home parenteral nutrition decreased their appetite, while others felt their appetite stayed the same (15).

Quality of life is defined as enjoying life, being happy and satisfied with life, and being able to do what you want to do when you want to do it (11). Health-related quality of life refers to the way in which illness, pain, motor activity reduction and unease all impose limitations or modifications on daily behavior, social activities, psychological well-being, and other aspects of an individual's life (12). When it comes to nutrition, eating is a pleasure and a social tradition. When a patient is on home nutrition support, the pleasure and social roles of eating disappear. Some patients have reported that they feel excluded from meals and events that involve food. Their quality of life is affected by their inability to taste, swallow, and drink (6). It has been shown that being at home and having greater independence is associated with improved quality of life (11), especially in oncology patients (12). However, only patients who live with home nutritional support longer than three months get the full benefits when it comes to quality of life (14). Home enteral tube feedings can have a physiological effect on patients' nutritional status because it gives them the comfort of knowing that they are getting the nutrients they need on a daily basis (13). One study showed that patients on home parenteral nutrition felt safe and secure that their nutrient needs were being met intravenously (11). Another study stated that home parenteral nutrition may help to prolong a patient's life for more than seven months as well as improve their quality of life or at least maintain it until two months prior to death. Bozzetti et al found that many patients on home parenteral nutrition had feelings of anxiety and depression (14). Both patients and family members in a study described home parenteral nutrition as having a direct and positive effect on quality of life (15). Enteral nutrition and parenteral nutrition improve health status and quality of life, but increase morbidity, iatrogenic side effects, and mortality. Parenteral

nutrition can negatively affect quality of life when it is associated with unintended outcomes such as burden on the patient and family, catheter-related sepsis, thrombosis, or metabolic complications (11). A patient's quality of life can also be affected by the discomfort of a tube and a change in body image with the presence of a tube. Many patients feel very uncomfortable with other people seeing the tube in their nose. It can also limit a patient's physical activities and make them feel like they are trapped at home. Home enteral tube feeding can even cause psychological problems related to the inability to eat, which many patients consider a major loss (6).

Overall, both enteral and parenteral nutrition support have been shown to be beneficial, but there will always be some complications with both types. Each patient has a different set of needs and may require a different type of nutrition support based on those needs.

CHAPTER II

METHODS

Research Design

Many studies have examined the use of parenteral and enteral nutrition separately. There have been no recent studies that focus on the preference of all of the people involved in the care of the child being given parenteral or enteral nutrition support. The purpose of this research was to study if pediatric hematopoietic stem cell transplant parents/caregivers, physicians, and nurses prefer parenteral nutrition or enteral nutrition, their feelings toward both types of nutrition support, goals regarding nutrition, and how the medical team could help meet those goals.

Participants

The study included caregivers, physicians, and nurses on the hematopoietic stem cell transplant unit at St. Jude Children's Research Hospital. Participants were asked to be involved in the study on a voluntary basis. There were 40 physicians and nurses and 31 caregivers surveyed in the study. Of all of the healthcare professionals that were e-mailed the survey, only 15 filled out every single question in the survey. Each caregiver that was asked to fill out the survey agreed to participate. There were a total of 17 males and 54 females. The ages ranged from 22 to 59 years old.

Measurements

The information was gathered from a questionnaire that all participants filled out. All questions were open-ended so that each participant could voice their full opinion

without being guided into a particular answer. Their answers were anonymous, but they were placed into a category of parent/caregiver or healthcare professional. The information was then compiled into those categories and evaluated. The first question in both surveys asked the participant for their consent so an official consent form was waived. IRB approval was obtained from both the University of Memphis and St. Jude Children's Research Hospital.

Procedures

Caregivers, physicians, and nurses were asked to fill out an electronic survey through kwiksurveys.com. Each physician and nurse was e-mailed the survey. The survey was e-mailed through the St. Jude Children's Research Hospital hematopoietic stem cell transplantation group on three separate occasions. The e-mails were all sent one week apart from each other. Each caregiver was visited in person and asked to fill out the survey. The interviewer was present throughout the duration of the caregivers' survey to answer any possible questions. After all of the questionnaires were completed, the interviewer collected and compiled the data for evaluation.

CHAPTER III

RESULTS

Introduction

This research looked at the preference of parenteral and enteral nutrition support of caregivers, physicians, and nurses exclusively in the hematopoietic stem cell transplant unit at St. Jude Children's Research Hospital. There were two separate surveys given. One survey was for caregivers, while the other survey was filled out by physicians and nurses. There were twelve research questions that guided each survey. Each research question for each survey is addressed individually in this section.

Caregiver Survey Research Questions

Research question 1

What are your goals regarding your child's nutrition during treatment?

When asked about their goals regarding their child's nutrition during cancer treatment, the caregivers responded with quite a few answers. Table 1 shows the caregivers' goals regarding their child's nutrition during their treatment in the hematopoietic stem cell transplant unit at St. Jude Children's Research Hospital.

Table 1. Caregivers' Goals Regarding Their Child's Nutrition During Treatment

Category	n	%
Maintain weight	13	34
Eat enough calories	11	29
Avoid/get off TPN	5	13
Eat healthy	5	13
Help healing/recovery	2	5
Like cafeteria food	1	3
Keep bones and muscles healthy	1	3
Total n = 31		

n = total number of responses in that category for questions asked.

The majority of the caregivers wanted their children to maintain his or her weight during their treatment and hospital stay. Another frequent goal was for the children to start eating more and to get enough calories. The caregivers obviously want their children to get enough nutrients so that they can maintain their weight, which seems to go hand in hand with eating enough calories. Other caregivers just wanted their children to be able to avoid having to be on parenteral nutrition or to get off parenteral nutrition if they were already on it. A few caregivers' goals were to make sure that their children were eating healthy, recovering on schedule, liking what was offered to them from the cafeteria, and keeping their bones and muscles healthy. It looks like the main goal overall was to keep the children in a healthy state during treatment.

Research question 2

Have those goals been met?

When asked about whether or not their goals have been met, most of the caregivers said they were satisfied. Table 2 shows the caregivers' responses to whether or not their goals have been met in the hematopoietic stem cell transplant unit at St. Jude Children's Research Hospital.

Table 2. Caregivers' Responses to Whether or Not Their Goals Have Been Met

Category	n	%
Yes	21	68
Almost	7	22
No	3	10
Total n = 31		

n = total number of responses in that category for questions asked.

Over 50% of the caregivers felt as though their goals had been met by the medical team. Some others said their goals had almost been met or were in the process of being met. Very few caregivers stated that their goals had not been met.

Research question 3

How do you think the medical team (doctor, nurse, dietitian) can help you to meet those goals?

When asked about how the medical team can help meet their goals, the caregivers all had different answers. Table 3 shows the caregivers' responses to how the medical

team can help meet their goals in the hematopoietic stem cell transplant unit at St. Jude Children's Research Hospital.

Table 3. Caregivers' Responses to How the Medical Team Can Help Meet Their Goals

Category	n	%
They have done a great job	12	38
Sharing knowledge/answering questions	9	28
Calorie counts/monitoring nutrition	3	9
Getting food the patients like	3	9
Emphasizing eating healthy	2	6
Alter TPN/TF as needed	2	6
Not sure	1	3
Total n = 31		

n = total number of responses in that category for questions asked.

The majority of the caregivers stated only that the medical team had done a great job in helping to meet their goals and gave no suggestions or ways to help meet goals in the future. Some caregivers stated that it would help them if the medical team shared their knowledge and answered any questions they may have. Other caregivers thought that calorie counts and offering foods the children like would be beneficial. A few caregivers' wanted the medical team to emphasize eating healthy and alter nutrition support as

needed. One caregiver stated he or she was unsure how the medical team could help meet their goals.

Research question 4

What do you know about parenteral nutrition (TPN), a way of supplying all the nutritional needs of the body by bypassing the digestive system and supplying nutrients through a catheter placed in a large vein?

When asked what they know about parenteral nutrition, more than half of the caregivers had some knowledge on the subject. Table 4 shows the caregivers' responses to what they know about parenteral nutrition.

Table 4. What Caregivers Know About Parenteral Nutrition

Category	n	%
Know something	20	67
Not much	10	33
Total n = 30		

n = total number of responses in that category for questions asked.

The majority of the caregivers stated they either knew only that parenteral nutrition is a nutritional supplement or that they did not know much about it. Some caregivers knew how to hook up and unhook parenteral nutrition. Other caregivers stated that they were very familiar with it. A couple caregivers knew that it was given through a vein. One caregiver stated he or she had been using it for three months and one other caregiver stated that he or she did not think it was as good as regular food. It seems as

though most caregivers do not really know what parenteral nutrition is and should be educated on it.

Research question 5

Have you had any previous experience with parenteral nutrition (TPN)? If so, was it good or bad?

When asked about their previous experience with parenteral nutrition, most of the caregivers had no experience. Table 5 shows the caregivers' previous experiences with parenteral nutrition.

Table 5. Caregivers' Previous Experience with Parenteral Nutrition

Category	n	%
No experience	18	56
Good experience	7	22
Okay experience	6	19
Bad experience	1	3
Total n = 31		

n = total number of responses in that category for questions asked.

The majority of caregivers had no experience at all with parenteral nutrition. Some caregivers had good experiences with it, while others stated they had an okay experience with parenteral nutrition. One caregiver stated he or she had a bad experience with parenteral nutrition. The majority of caregivers who had some kind of experience with parenteral nutrition did not have a bad experience with it.

Research question 6

If you have previous experience with parenteral nutrition (TPN), how long was your child on it?

When asked how long their child had been on parenteral nutrition, almost all of the caregivers' children had never been on parenteral nutrition before. Table 6 shows the caregivers' responses to how long their child has been on parenteral nutrition.

Table 6. Caregivers' Response to How Long Their Child Was On Parenteral Nutrition

Category	n	%
Not applicable	18	60
1-2 weeks	4	13
3 months	3	10
1 month	2	7
A few weeks	2	7
4 months	1	3
Total n = 30		

n = total number of responses in that category for questions asked.

The majority of the caregivers were not applicable for this question because their child had not been on parenteral nutrition. Some caregivers' children had been on parenteral nutrition for one to two weeks. Other caregivers' children had been on it for about three months. A few caregivers' children had been on parenteral nutrition for around one month or a few weeks. One caregiver stated the child had been on it for four

months. None of these children were on parenteral nutrition for more than four months. Therefore, all of the children were on parenteral nutrition for a short amount of time.

Research question 7

Are there any reasons you would not want parenteral nutrition (TPN) for your child?

When asked about reasons they would not want their child to be on parenteral nutrition, many of the caregivers had no reasons to be against it. Table 7 shows the caregivers' reasons for not wanting their child on parenteral nutrition.

Table 7. Caregivers' Reasons for Not Wanting Parenteral Nutrition for Their Child

Category	n	%
None	18	53
Bad for liver/stressful on body	4	12
Child cannot eat on his/her own	4	12
No appetite/too full/child will not eat	4	12
Lose digestive function	3	9
Line infections	1	2
Total n = 31		

n = total number of responses in that category for questions asked.

The majority of the caregivers stated they had no reasons to not want parenteral nutrition for their children. Some caregivers stated that it was bad for their children's

liver and stressful on their body. Other caregivers thought that it caused their children to not be able to eat on their own or decrease their appetite. A few caregivers stated it made their children lose digestive function. One caregiver stated it causes line infections. Overall most caregivers would be okay with their children having parenteral nutrition.

Research question 8

What do you know about enteral nutrition (tube feedings), a way of providing food through a tube placed in the nose, stomach, or small intestine?

When asked what they know about enteral nutrition, more than half of the caregivers stated that they knew nothing about it. Table 8 shows the caregivers' responses to what they know about enteral nutrition.

Table 8. What Caregivers' Know About Enteral Nutrition

Category	n	%
Nothing	19	61
Know something	12	39
Total n = 31		

n = total number of responses in that category for questions asked.

The majority of the caregivers stated they know nothing about enteral nutrition. Some caregivers stated that they have worked with enteral nutrition in the past or know something about it. Other caregivers stated that it is a nutrition supplement when a person cannot eat orally. One caregiver stated it makes the stomach full and the children will not

eat because of it. It seems that most caregivers know nothing about enteral nutrition and need to be educated on it.

Table 9 shows a comparison between caregivers' knowledge of parenteral nutrition and enteral nutrition.

Table 9. Caregivers' Knowledge of Parenteral Nutrition and Enteral Nutrition

	n	%
Parenteral nutrition	20	63
Enteral nutrition	12	37
Total n = 31		

n = total number of responses in that category for questions asked.

More caregivers have some knowledge of parenteral nutrition than knowledge of enteral nutrition. This may be because parenteral nutrition was used more often than enteral nutrition.

Research question 9

Do you have any previous experience with enteral nutrition (tube feedings)?

When asked about their previous experience with enteral nutrition, most of the caregivers had no experience with it. Table 10 shows the caregivers' responses to whether or not they had previous experiences with enteral nutrition.

Table 10. Caregivers' Previous Experience with Enteral Nutrition

Category	n	%
No	21	68
Yes	10	32
Total n = 31		

n = total number of responses in that category for questions asked.

The majority of caregivers had no previous experience with enteral nutrition. However, quite a few caregivers did have experience with it.

Table 11 shows a comparison between caregivers' experience with parenteral nutrition and enteral nutrition.

Table 11. Caregivers' Experience with Parenteral Nutrition and Enteral Nutrition

	n	%
Parenteral nutrition	14	58
Enteral nutrition	10	42
Total n = 24		

n = total number of responses in that category for questions asked.

This shows that more caregivers have had some kind of experience with parenteral nutrition than with enteral nutrition.

Research question 10

If you have previous experience with enteral nutrition (tube feedings), how long was your child on it?

When asked about the length of time their child had been on enteral nutrition, over three-fourths of the caregivers' children had never been on enteral nutrition at all. Table 12 shows the caregivers' responses to how long their child has been on enteral nutrition.

Table 12. Caregivers' Responses to How Long Their Child Was On Enteral Nutrition

Category	n	%
Not applicable	24	77
A couple of weeks	2	7
4 weeks	2	7
Several years	1	3
2 months	1	3
Less than 12 hours	1	3
Total n = 31		

n = total number of responses in that category for questions asked.

The majority of the caregivers were not applicable for this question because their children had never been on enteral nutrition. A couple caregivers' children had been on enteral nutrition for a couple of weeks up to four weeks. One caregiver stated his or her child had been on it for several years. Another caregiver's child had been on it for two

months. The last caregiver's child had been on it for less than 12 hours. The majority of the children who had been on enteral nutrition at some point were on it during a short term period.

Research question 11

Are there any reasons you would not want enteral nutrition (tube feeding) for your child?

When asked what reasons would cause them to not want enteral nutrition for their child, over half of the caregivers had no reasons. Table 13 shows the caregivers' reasons for not wanting their child on enteral nutrition.

Table 13. Caregivers' Reasons for Not Wanting Their Child on Enteral Nutrition

Category	n	%
None	21	66
If the child can eat	4	13
It decreases appetite	2	6
Risk of infection	2	6
It hurts/invasive	2	6
Vomiting	1	3
Total n = 31		

n = total number of responses in that category for questions asked.

The majority of the caregivers had no reasons for not wanting their children to have enteral nutrition if necessary. Some caregivers would not want enteral nutrition for

their child if the child could eat. Other caregivers would not want it because they stated it decreases appetite. A couple caregivers stated they did not want it because of its risk for infection or that it is too invasive. One caregiver would not want it because it causes vomiting.

Research question 12

If given the choice, which would you prefer: parenteral nutrition (TPN) or enteral nutrition (tube feeding)?

When asked which type of nutritional support they preferred, most of the caregivers said they would prefer parenteral nutrition. Table 14 shows the caregivers' preferences between parenteral nutrition and enteral nutrition.

Table 14. Caregivers' Preferences of Parenteral Nutrition or Enteral Nutrition

Category	n	%
Parenteral Nutrition	21	70
Unsure	5	17
Enteral nutrition	3	10
Depends on the child's needs	1	3
Total n = 30		

n = total number of responses in that category for questions asked.

The majority of the caregivers would choose parenteral nutrition over enteral nutrition when given the choice. Some caregivers were unsure which type of nutritional support they would choose or stated that it would depend of the child's nutritional needs.

Healthcare Professional Survey Research Questions

Research question 1

What are your goals regarding your patients' nutrition during treatment?

When asked what their goals were regarding their patients' nutrition during treatment, the healthcare providers had several different answers. Table 15 shows the healthcare providers' goals regarding their patients' nutrition during treatment in the hematopoietic stem cell transplant unit at St. Jude Children's Research Hospital.

Table 15. Healthcare Professionals' Goals Regarding Their Patients' Nutrition During Treatment

Category	n	%
Optimal nutrition	13	46
To eat when they are hungry	3	10
Maintain weight	3	10
Provide appetite stimulants	2	7
Provide meals in a timely manner	2	7
Provide IV nutritional support	1	4
Metabolic stability	1	4
Provide education to families	1	4
High caloric intake due to harshness of chemo	1	4
Satisfy patient preferences	1	4
Total n = 23		

n = total number of responses in that category for questions asked.

The majority of the healthcare professionals wanted their patients to get optimal nutrition. Other healthcare professionals wanted their patients to eat when they are hungry and maintain their weight. Some healthcare professionals' goals were to provide appetite stimulants when needs and try to provide meals in a timely manner. A few healthcare professionals stated their goals were to provide IV nutritional support for their patients, help patients maintain metabolic stability, provide education to families, provide high caloric intake for patients, and satisfy patient preferences. It seems as though the healthcare professionals had many different goals for their patients.

Research question 2

Are those goals usually met?

When asked if their goals were met, most of the healthcare providers answered yes. Table 16 shows the healthcare providers' responses to whether or not their goals were met.

Table 16. Healthcare Professionals' Responses to Goals Being Met

Category	n	%
Yes	16	64
Sometimes	6	24
No	3	12
Total n = 23		

n = total number of responses in that category for questions asked.

Over 50% of the healthcare professionals felt as though their goals were usually met. Some others said their goals had been met sometimes or most of the time. A couple healthcare providers stated their goals were not usually met. One healthcare professional stated that goals were eventually met or not met as quickly as preferred and another stated goals were met as well as expected.

Research question 3

How do you think we can better meet these goals?

When asked how their goals could be better met, quite a few of the healthcare providers had no suggestions. Table 17 shows the healthcare providers' responses to how their goals can be better met.

Table 17. Healthcare Professionals' Responses to How Their Goals Can Be Better Met

Category	n	%
No suggestions	10	42
Better communication/education with families	4	17
24 hour nutrition services	2	8
Supplying requested food	2	8
Offer more ethnic foods	2	8
TPN works well	1	4
Better food options/cooking area for parents	1	4
Pay close attention to increased caloric requirements	1	4
Utilize EN earlier	1	4
Total n = 22		

n = total number of responses in that category for questions asked.

The majority of the healthcare professionals had no suggestions on how their goals can be better met in the future. Some healthcare professionals stated that it would be helpful if there was better communication with the patients' families. Other healthcare professionals thought that nutrition services should be available twenty-four hours every day and requested food, along with ethnic foods, should be supplied for the patients. A few healthcare professionals thought that some type of nutrition support helps meet goals,

as well as supplying a cooking area for parents, and paying close attention to caloric needs for each patient.

Research question 4

What is your opinion on parenteral nutrition?

When asked what their opinions on parenteral nutrition were, the healthcare providers responded in many different ways. Table 18 shows the healthcare providers' opinions on parenteral nutrition.

Table 18. Healthcare Professionals' Opinions on Parenteral Nutrition

Category	n	%
Necessary	5	25
Should be used as a last resort	4	20
Appropriate at St. Jude	3	15
Necessary in some cases but not all	2	10
Great short term option	2	10
Solves nutrition needs	2	10
Not the best approach but useful	1	5
Great	1	5
Total n = 20		

n = total number of responses in that category for questions asked.

The majority of the healthcare professionals stated that parenteral nutrition is necessary in many cases. Some healthcare professionals thought that it should only be

used as a last resort, but is appropriate at St. Jude. Other healthcare professionals stated it is necessary in some cases, but not in all cases. It was also stated that it is a great short term option that solves nutritional needs. One healthcare professional stated that it was useful, but not the best approach, while another said it was great. It seems that there are many differing opinions on parenteral nutrition among the healthcare professionals.

Research question 5

Please list all reasons for NOT initiating parenteral nutrition.

When asked what their reasons would be for not initiating parenteral nutrition, all of the healthcare providers' answers varied. Table 19 shows the healthcare providers' reasons for not initiating parenteral nutrition.

Table 19. Healthcare Professionals' Reasons for Not Initiating Parenteral Nutrition

Category	n	%
Hard on liver	6	19
None	4	13
Patient is eating	4	13
Gut is intact	3	10
Family is against it	3	10
Risk of infection	2	7
Difficulty stimulating appetite/oral aversions	2	7
Stable weight/nutrition status	2	7
Poor line access	1	3
Cost	1	3
Decreased freedom	1	3
Creates dry mouth	1	3
Gut is not working	1	3
Total n = 19		

n = total number of responses in that category for questions asked.

The healthcare professionals gave many different reasons for not wanting to initiate parenteral nutrition with their patients. The majority of the healthcare professionals stated they would not want to initiate because it is hard on the liver. Some healthcare professionals stated they had no reasons to not want to initiate it. Other

healthcare professionals would not initiate it if the patient was eating, had a stable weight, their gut was working, the family was against it, or the risk of infection. A few healthcare professionals stated it made stimulating the patients' appetites more difficult. One healthcare professional would not initiate it due to poor line access, while another was concerned about the cost. The other answers included decreased freedom of the patient while hooked up to parenteral nutrition, the fact that it may cause dry mouth, and if the gut is not working.

Research question 6

Please list all reasons FOR initiating parenteral nutrition.

When asked what their reasons for initiating parenteral nutrition are, the healthcare providers had quite a few answers. Table 20 shows the healthcare providers' reasons for initiating parenteral nutrition with their patients.

Table 20. Healthcare Professionals' Reasons for Initiating Parenteral Nutrition

Category	n	%
Loss of appetite/inability to eat	14	43
Weight loss	8	24
Ability to alter electrolytes	3	9
Unable to tolerate EN	3	9
Gut not working	2	6
When needed	1	3
Vomiting/diarrhea	1	3
Unknown	1	3
Total n = 19		

n = total number of responses in that category for questions asked.

The majority of the healthcare professionals stated they would initiate parenteral nutrition is the patient could not physically eat or had no appetite. Some healthcare professionals would initiate it if the patient had lost quite a bit of weight and was not gaining it back adequately. Other healthcare professionals would initiate it to help control the patients' electrolytes. A few healthcare professionals would initiate it if the patient was unable to tolerate enteral nutrition or their gut was not working. One healthcare professional stated he or she would initiate it if it was needed, while another would initiate it if the patient had uncontrollable vomiting and diarrhea.

Research question 7

What is your preferred range of time that a patient should be on parenteral nutrition?

When asked what range of time they preferred a patient to be on parenteral nutrition, many of the healthcare providers had no preference. Table 21 shows the healthcare providers' preferred range of time that a patient should be on parenteral nutrition if needed.

Table 21. Healthcare Professionals' Preferred Range of Time That a Patient Should Be On Parenteral Nutrition

Category	n	%
No preference	5	26
Until appetite comes back	3	16
2-3 weeks	2	11
No more than 3 months	2	11
Depends on the patient	2	11
Until 75% caloric intake is maintained	1	5
1 month	1	5
1-2 months	1	5
6-8 weeks	1	5
1-2 weeks	1	5
Total n = 19		

n = total number of responses in that category for questions asked.

The majority of the healthcare professionals stated that they had no preferred range of time that a patient should be on parenteral nutrition. Other healthcare professionals would keep a patient on parenteral nutrition until his or her appetite came back or until the patient could eat about 75% of their intake orally. Most of the other healthcare professionals gave a preferred range of around less than three months, while a couple others preferred no longer than a couple weeks.

Research question 8

What is your opinion on enteral nutrition?

When asked about their opinion on enteral nutrition, the healthcare providers had many different answers. Table 22 shows the healthcare providers' opinions on enteral nutrition.

Table 22. Healthcare Professionals' Opinions on Enteral Nutrition

Category	n	%
Great option	4	22
Best route	3	16
Do not like it	3	16
Helpful to supplement diet	2	11
Not applicable	2	11
Less costly	1	6
Better for liver	1	6
In favor of night feeds only	1	6
Underutilized	1	6
Total n = 16		

n = total number of responses in that category for questions asked.

The majority of the healthcare professionals stated they like enteral nutrition or think it is the best route for nutrition support. Some healthcare professionals stated that it is a helpful way to supplement a patient's diet. A couple healthcare professionals stated that they do not like enteral nutrition. One healthcare professional stated it is less costly than parenteral nutrition, while another stated that it is better for the liver than parenteral nutrition. Other answers included only being in favor of feeding this way at night and not during the day and the fact that not every patient can tolerate enteral nutrition. The last opinion of enteral nutrition was that it is underutilized.

Research question 9

Please list all reasons for NOT initiating enteral nutrition.

When asked about reasons to not initiate enteral nutrition, the healthcare providers' opinions somewhat differed. Table 23 shows the healthcare providers' reasons for not initiating enteral nutrition in their patients.

Table 23. Healthcare Professionals' Reasons for Not Initiating Enteral Nutrition

Category	n	%
Unable to tolerate/abdominal pain/nausea/vomiting/GVHD	9	45
None	4	20
Comfort issue/family issue	2	10
Trauma of placement	2	10
Gut not working	2	10
Keeps kids from being active	1	5
Total n = 16		

n = total number of responses in that category for questions asked.

The majority of the healthcare professionals would not initiate enteral nutrition if the patient was unable to tolerate it. Some healthcare professionals had no reasons to not initiate enteral nutrition. Other healthcare professionals would not initiate it because if the patient's family had a problem with it or if the patient was traumatized by it. A couple healthcare professionals stated they would not initiate it if the gut was not working. One

healthcare professional would not initiate it because it keeps the patients from being active.

Research question 10

Please list all reasons FOR initiating enteral nutrition.

When asked about reason to initiate enteral nutrition, the healthcare providers had a few different answers. Table 24 shows the healthcare providers' reasons to initiate enteral nutrition in their patients.

Table 24. Healthcare Professionals' Reasons for Initiating Enteral Nutrition

Category	n	%
Weight loss/not eating/not enough calories	8	42
Keeps gut active	4	21
More natural/easier on liver	4	21
Cheaper	1	5
No other option	1	5
Not applicable	1	5
Total n = 16		

n = total number of responses in that category for questions asked.

The majority of the healthcare professionals stated they would initiate enteral nutrition if the patient was losing weight, not eating, or not getting enough calories. Some healthcare professionals would initiate enteral nutrition to keep the gut active. Other

healthcare professionals would initiate it because it is a more natural way of providing nutrition and it is easier on the liver. One healthcare professional would initiate it because it is cheaper, while another would initiate it if there was no other option.

Research question 11

What is your preferred range of time that a patient should be on enteral nutrition?

When asked about their preferred range of time that a patient should be on enteral nutrition, the healthcare providers mainly said until the gut can be used and the patient's appetite comes back. Table 25 shows the healthcare providers' preferred range of time that a patient should be on enteral nutrition.

Table 25. Healthcare Professionals' Preferred Range Of Time a Patient Should Be On Enteral Nutrition

Category	n	%
Until gut can be used/appetite is back	10	67
No preference	4	27
Until 75% caloric intake is maintained	1	6
Total n = 15		

n = total number of responses in that category for questions asked.

The majority of the healthcare professionals preferred that a patient be on enteral nutrition until the gut can be used or the patient's appetite comes back. A few healthcare professionals' had no preference on the range of time a patient should be on enteral

nutrition. One healthcare professional preferred a patient to be on enteral nutrition until 75% of the patient's caloric intake is maintained.

Research question 12

Which nutrition support method do you prefer: parenteral nutrition or enteral nutrition?

When asked whether they prefer parenteral nutrition or enteral nutrition, the healthcare providers' main answer was enteral nutrition. Table 26 shows the healthcare providers' preference between parenteral nutrition and enteral nutrition.

Table 26. Healthcare Professionals' Preference of Parenteral Nutrition or Enteral Nutrition

Category	n	%
Enteral nutrition	6	40
Depends on patient	5	33
Parenteral nutrition	3	20
No preference	1	7
Total n = 15		

n = total number of responses in that category for questions asked.

The majority of the healthcare professionals would choose enteral nutrition over parenteral nutrition when given the choice. Some healthcare professionals stated that it depended on the patient. One healthcare professional had no preference between the two types of nutrition support.

Table 27 shows a comparison between caregivers' and healthcare professionals' preference of nutrition support. It shows that caregivers tend to preferred parenteral nutrition over enteral nutrition, whereas healthcare professionals preferred enteral nutrition over parenteral nutrition when given a choice between the two types of nutrition support.

Table 27. Caregivers' vs. Healthcare Professionals' Preference of Parenteral Nutrition or Enteral Nutrition

	Caregivers	Healthcare Professionals
Preference of nutritional support	Parenteral nutrition	Enteral nutrition

CHAPTER IV

DISCUSSION

In this study, results indicate that most caregivers preferred parenteral nutrition over enteral nutrition, while most healthcare professionals preferred enteral nutrition over parenteral nutrition. There is reason to believe that caregivers may change their preference once they were educated more on the types of nutrition support. The outcome of the study may have been different if the caregivers understood the difference between the two types of nutrition support or had some previous experience with enteral or parenteral nutrition. This and the fact that most caregivers surveyed had never experienced their child being on parenteral nutrition or enteral nutrition may explain their responses. Therefore, the caregivers did not have all of the information needed to determine which type of nutrition support would be best for their child.

The results also showed that most caregivers' goals regarding nutrition included the patients maintaining their weight, eating enough calories, avoiding or getting off parenteral nutrition, and helping with quicker healing and recovery, which went hand in hand with the healthcare professionals' main goals of the patients maintaining an overall optimal nutrition status and maintain their weight. Most of the caregivers believed that the medical team was already doing a great job helping meet those goals. The caregivers' other suggestions for the medical team to help meet those goals included sharing knowledge, answering questions, and doing calorie counts. The healthcare professionals agreed with the caregivers again by having to suggestions for the medical team to help meet those goals because the majority of them were already met. However, some other suggestions included better communication and education with patients' families and

having nutrition services open twenty-four hours every day. It seems as though for the most part, the caregivers and healthcare professionals agreed on their goals regarding nutrition and how the medical team could help meet those goals.

The results in this study indicate that caregivers prefer parenteral nutrition over enteral nutrition. However, Asano and Rothpletz-Puglia found the opposite of these results. They found that caregivers prefer enteral nutrition once they understand the difference between the two types of nutrition support and the benefits of enteral nutrition. The parents of pediatric bone marrow transplant patients usually have an initial negative reaction to enteral nutrition, especially if the child fights it or has a negative reaction to the enteral nutrition, but Asano and Rothpletz-Puglia showed that three out of four parents changed their feelings toward enteral nutrition once the child was on it and they realized how easy it was to administer (4). These parents initially perceived enteral nutrition as a threat to the child's self image which put an additional emotional burden on them (4). These parents even reported that the child's nutritional status improved with enteral nutrition (4).

This study's results indicate that healthcare professionals prefer enteral nutrition to parenteral nutrition. This is consistent with the findings of Asano and Rothpletz-Puglia. Their pilot study found that oncologists were shown to prefer enteral nutrition over parenteral nutrition because enteral nutrition can help gastrointestinal function and has a beneficial effect on gut mucosal barrier function (4,2). Enteral nutrition was also preferred because it has been found to be more natural, less costly, and easier to provide (4,5,2).

The healthcare professionals seemed to have more varied answers than the caregivers. This may have been due to the fact that the healthcare professionals were able to take the survey on their own computer on their own time. The caregivers took the survey on the nutrition laptop while the interviewer waited for them to finish while clarifying any possible misunderstandings the caregiver had while taking the survey. This seemed to make a difference in the way the questions were answered because one survey was more controlled than the other survey.

Limitations

This study had a few limitations which may have affected the results and overall conclusion. The sample size of forty healthcare professionals and thirty-one caregivers was small. It also may not be a good representation of the bone marrow transplant population because only one hospital unit was surveyed over a six month period. Most of the caregivers surveyed had no experience with either type of nutrition support, so there were very few helpful responses received, which only led to the conclusion that caregivers need to be more educated on the subject. Patients whose caregivers were surveyed were very diverse because many of them were from countries other than the United States. Of the patients that were from the United States, they were from all different parts of the country. The patients also had different diagnoses and varying severities of their diseases, including acute lymphoblastic leukemia, acute myeloid leukemia, Hodgkin lymphoma, Ewing sarcoma, medulloblastoma, neuroblastoma, and myelodysplastic syndrome. Lastly, each patient's caregiver was surveyed during a different time of the patient's therapy. Therefore, all of these diagnoses and time periods

during the disease process were treated differently, so the patients may have had different issues and outcomes with nutrition support.

Conclusions

The findings of this study were a starting point to find out how to better help caregivers, physicians, and nurses in the bone marrow transplant unit. The study also gave us an idea of what type of nutrition support they prefer. Caregivers need to be educated more on nutrition support. It would be best if they were educated on the types of nutrition support before a decision is made on which type their child will receive. More studies need to be done including more participants. The caregivers' survey was more controlled and seemed to work better and be more consistent than the healthcare professionals' survey. Future studies should use the same controlled environment to survey healthcare professionals instead of allowing them to take it on their own time. Overall, the results were very helpful and will help make progress with nutrition support in pediatric bone marrow transplant patients.

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